

Bristol Testicular Cancer Service – Patient Survey 2012/13

Patient Survey Results

Questionnaires were given out to men attending the Bristol Testicular Cancer Service clinic from December 2012 until February 2013. Staff explained that participation in the survey was voluntary and a letter was attached to the front of the questionnaire explaining the survey in more detail. All answers were confidential, but there was the option of including contact details on a separate sheet so that participants could be informed of the findings of the survey. In total, 82 completed questionnaires were returned.

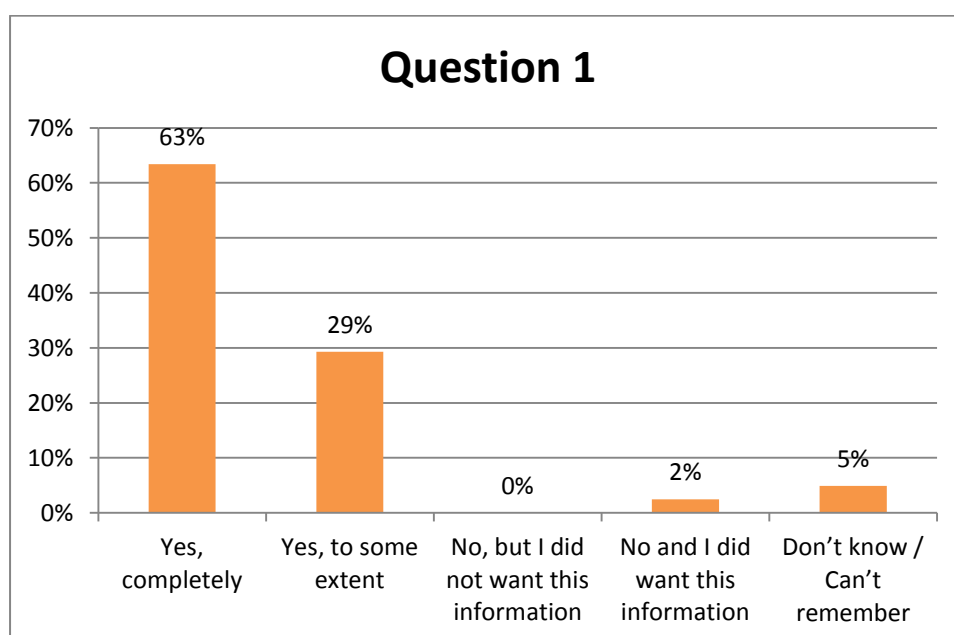
Analysis

Section 1 – Information and Support

(Questions relating to the first appointment in the Bristol Testicular Cancer Clinic and during treatment)

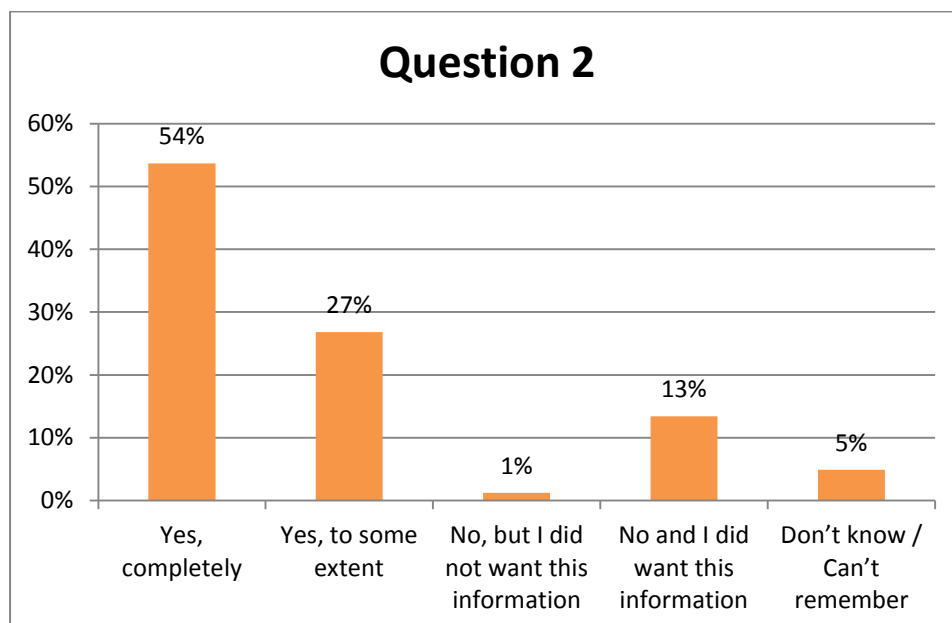
1. Have you been given information about the support available to you at diagnosis and during your treatment?

The majority of participants answered 'Yes, completely' (68%) or 'Yes, to some extent' (29%). Only 2 participants answered 'No and I did want this information' which represents less than 2% of the total.



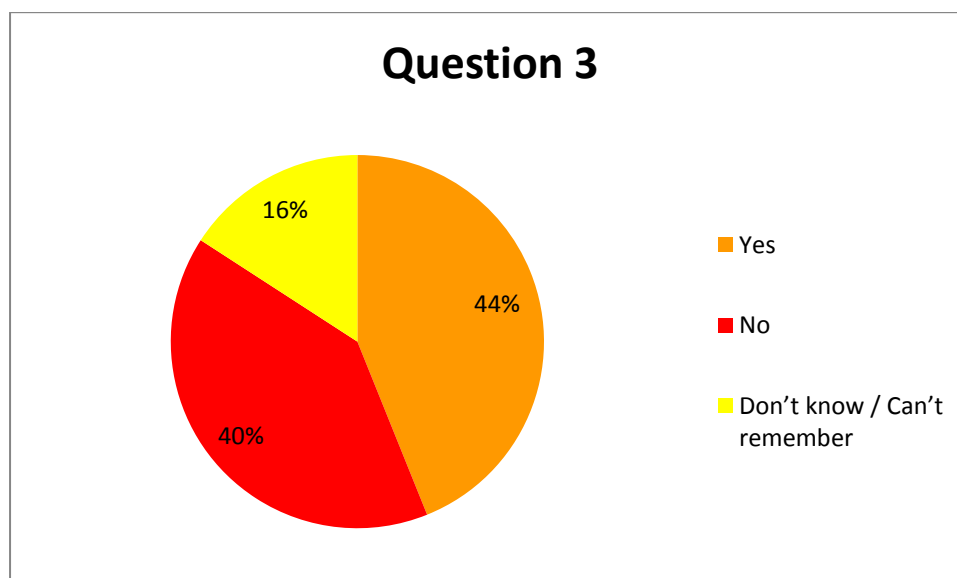
2. Have you been given information about support after you treatment?

Over half the participants answered 'Yes, completely' (54%) and 27% answered 'Yes, to some extent'. However 13% of participants answered 'No, and I did want this information'.



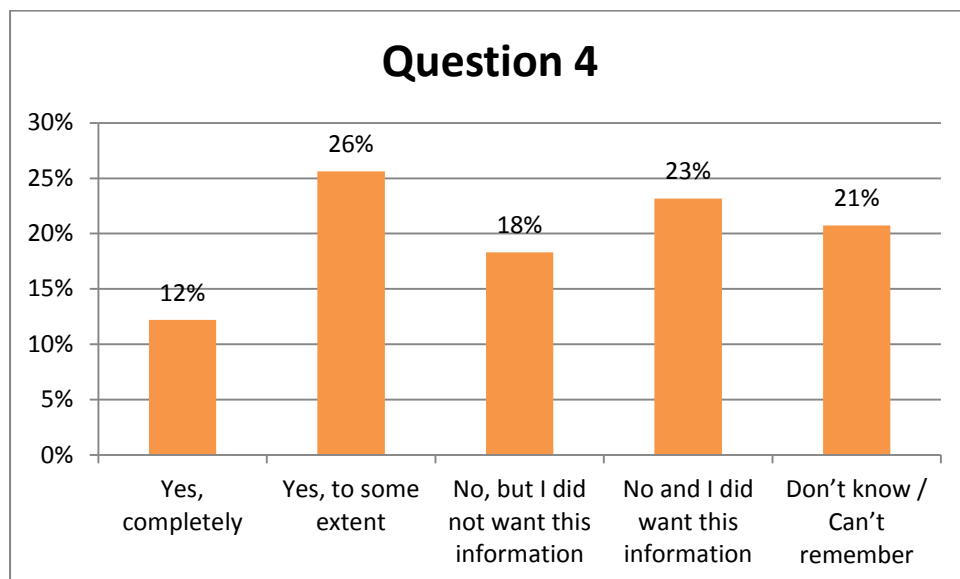
3. Did hospital staff tell you that you could get free prescriptions?

Over 30 participants answered 'No' to this question, which represents 40% of the total. 44% answered 'Yes', with the remaining 16% answering 'Don't know / can't remember'.



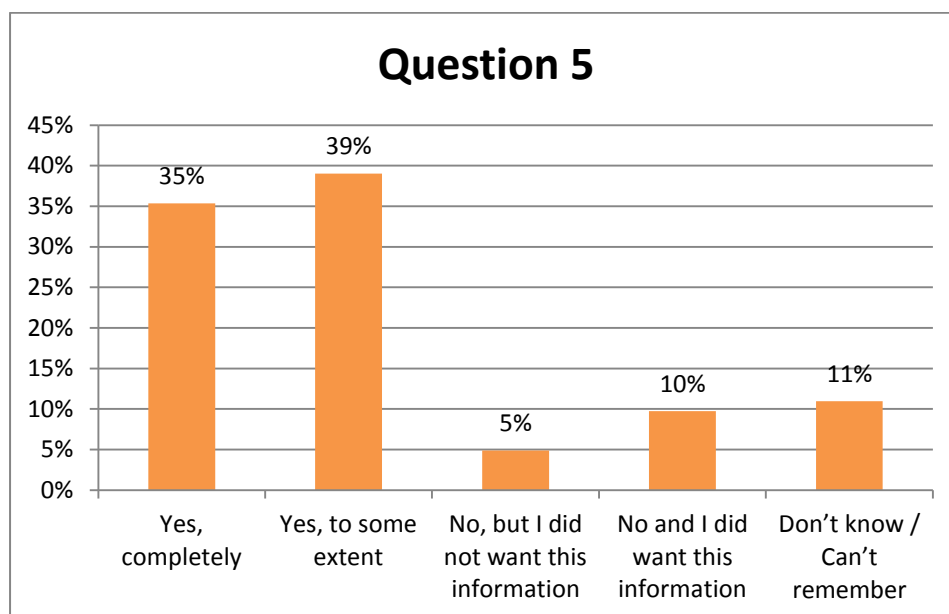
4. Did hospital staff give you information about how to get financial help or any benefits you might be entitled to?

Only 12% of participants answered 'Yes, completely' to this question, with 26% answering 'Yes, to some extent'. 23% answered 'No, and I did want this information'.



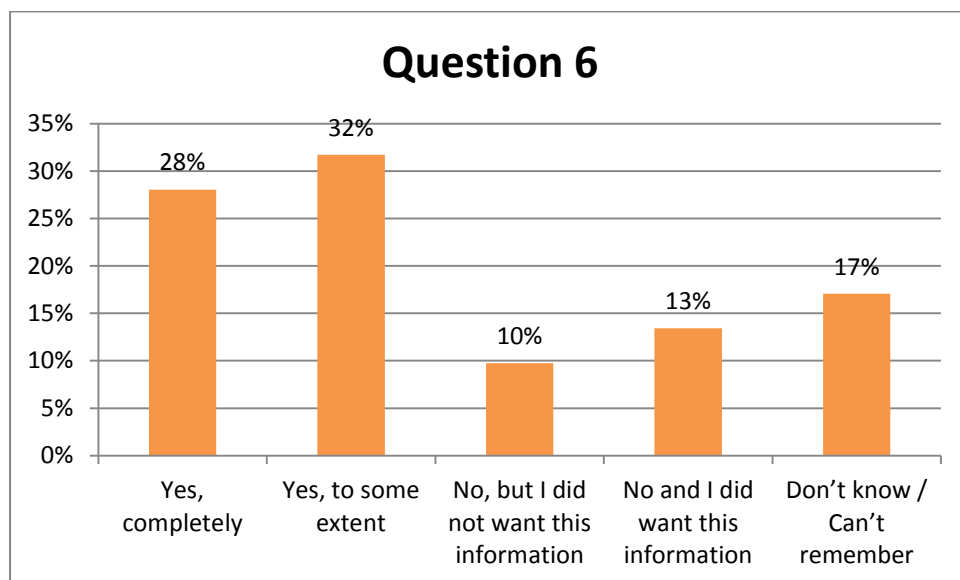
5. Did hospital staff give you information about support or self-help groups for people with cancer?

Almost 75% of participants answered 'Yes, completely' or 'Yes, to some extent'. However 10% did answer 'No, and I did want this information'.



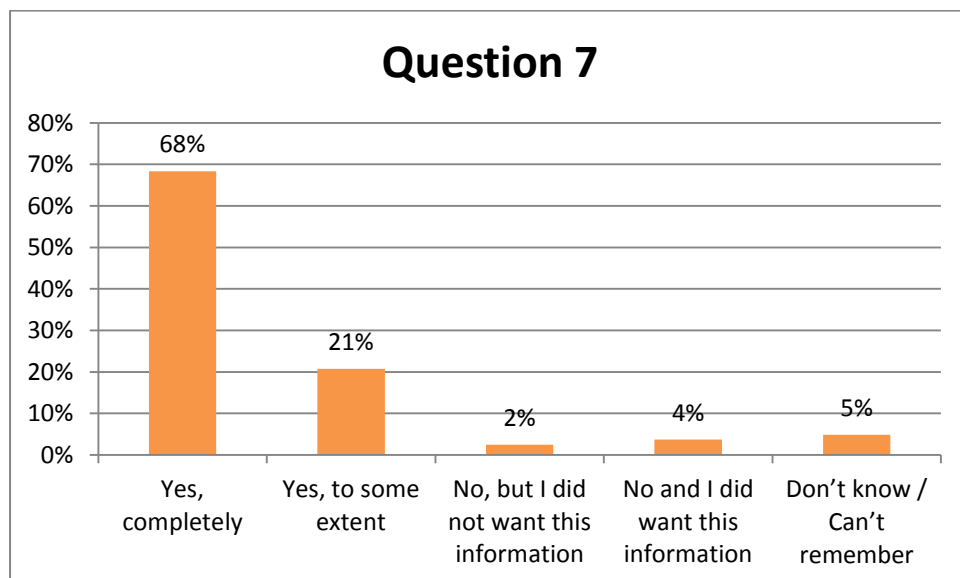
6. Did hospital staff give you information about how to get psychological and emotional support?

60% of participants answered 'Yes, completely' or 'Yes, to some extent'. However, 13% answered 'No, and I did want this information'



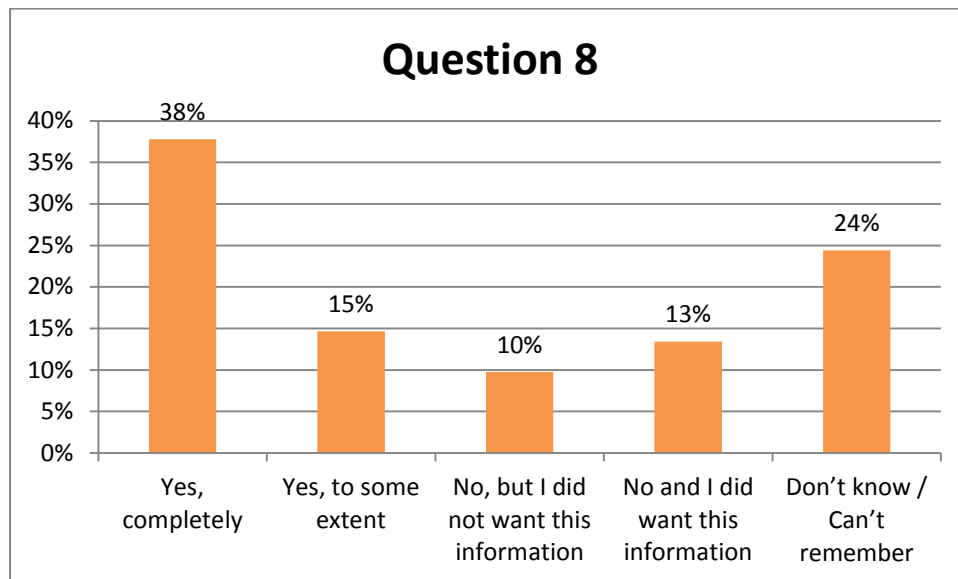
7. Did hospital staff give you information about sexuality and fertility?

68% of participants answered 'Yes, completely' and if the 'Yes, to some extent' is added, this equals 89% of participants. Only 4% answered 'No, and I did want this information'.



8. Did hospital staff give you information about the website?

38 % of participants answered 'Yes, completely', with a further 15% answering 'Yes, to some extent'. However 13% answered 'No, and I did want this information' and almost a quarter of participants answered 'Don't know / can't remember'.

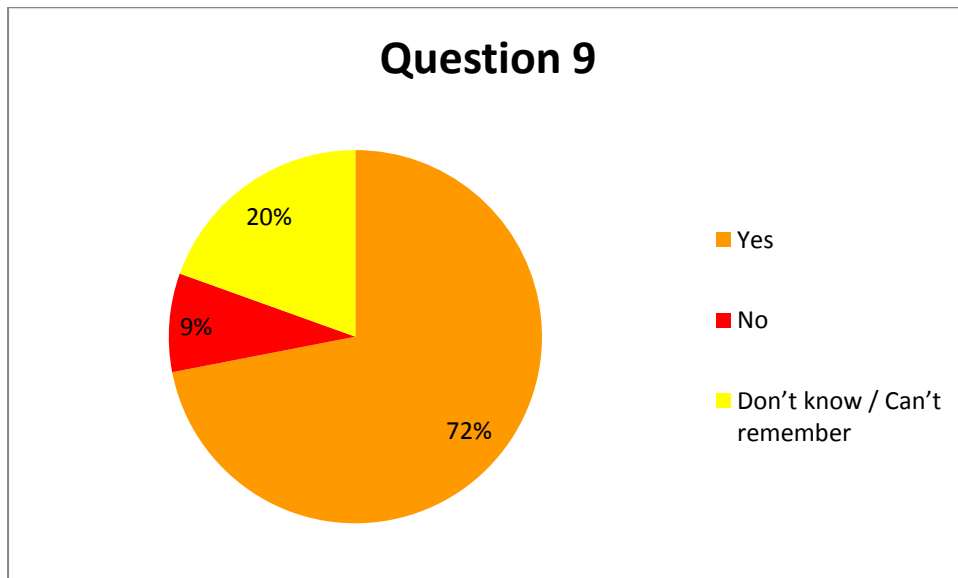


- Generally positive – good information at diagnosis and during treatment
- **Sexuality and fertility** – very well informed
- **Psychological and emotional support and self-help groups** – almost half participants indicated that they were not given enough detail about these sources of support or were not given any information

Section 2 – Clinical Nurse Specialist (Key Worker)

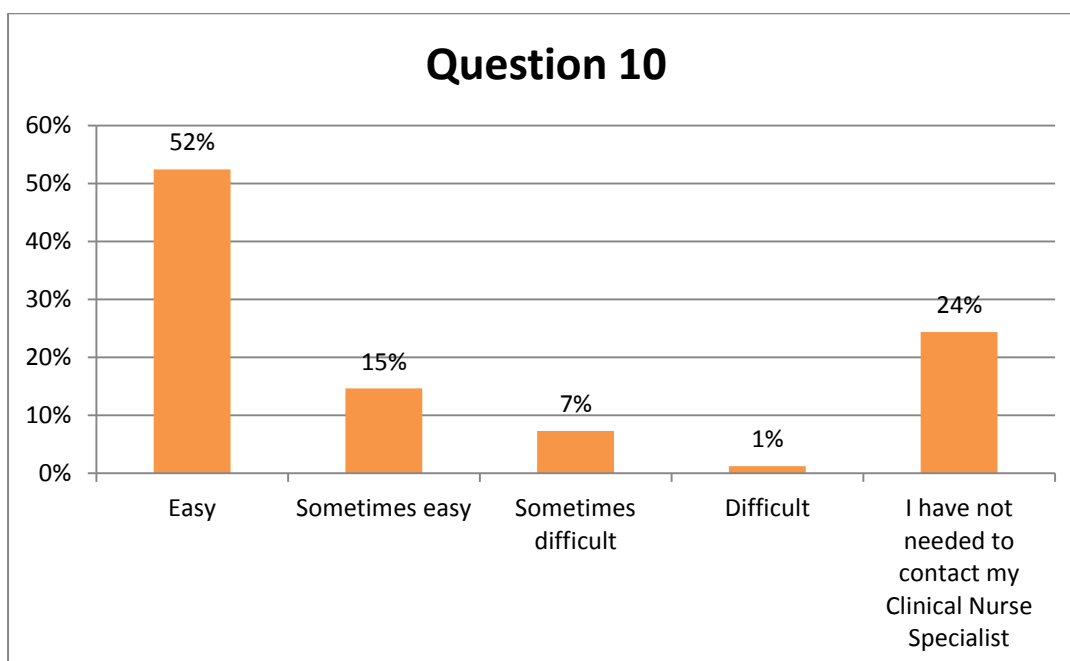
9. Were you given the name of a Clinical Nurse Specialist (key worker) who would be in charge of your care?

72% of participants answered 'Yes' to this question, with only 9% answering 'No'. The remainder of the participants answered 'Don't know / Can't remember'.



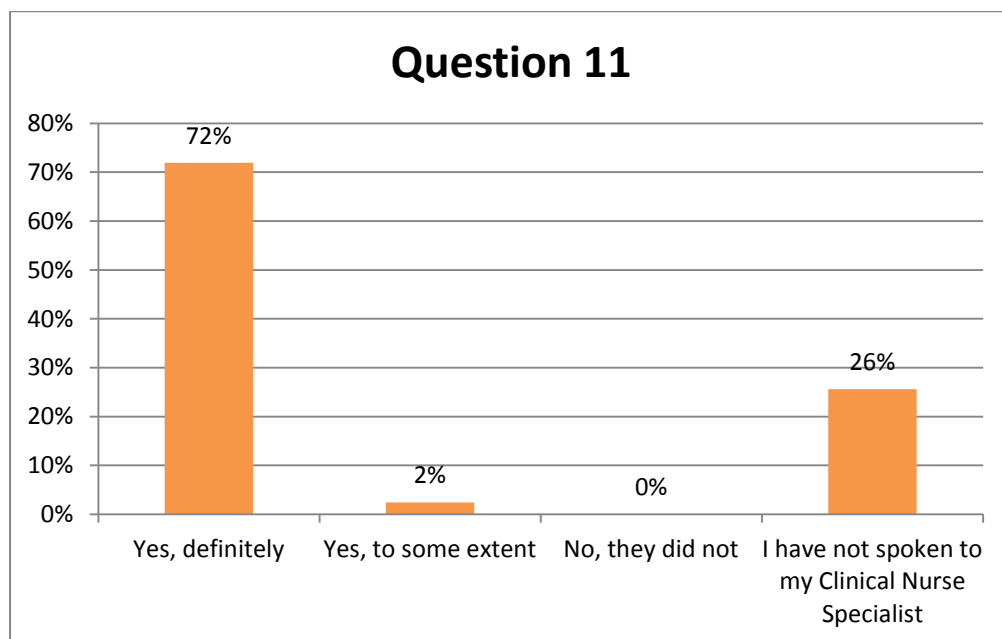
10. How easy is it for you to contact your Clinical Nurse Specialist?

24% answered 'I have not needed to contact my Clinical Nurse Specialist'. Out of the remaining 76%, almost one third answered 'Sometimes easy', 'sometimes difficult' or difficult.



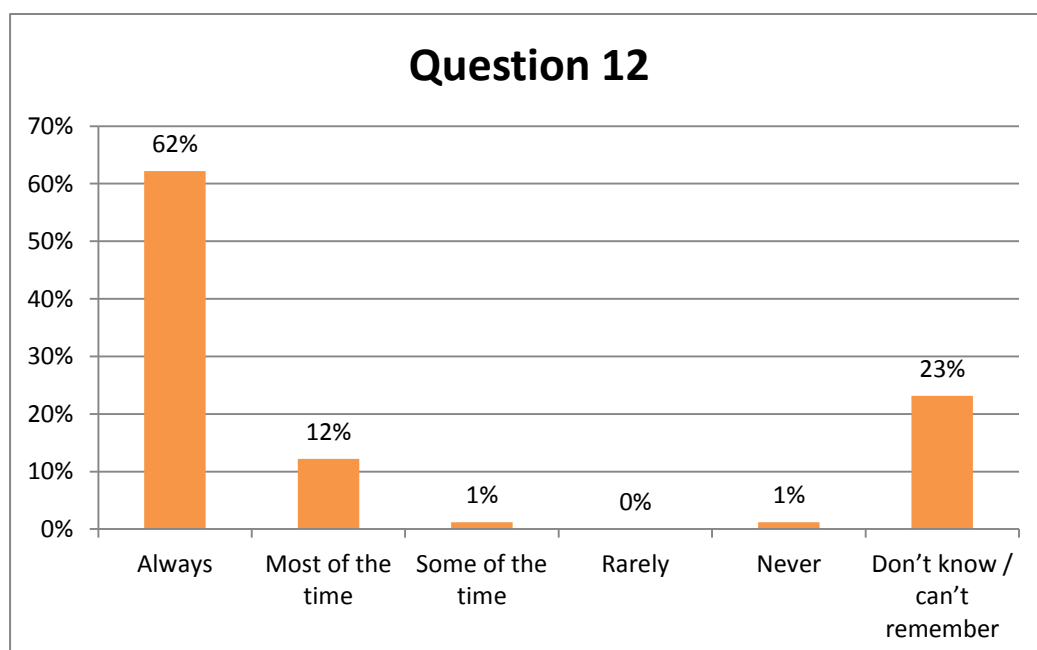
11. The last time you spoke to your Clinical Nurse Specialist, did she/he listen carefully to you?

72% participants answered 'Yes, definitely' with a further 2% answering 'Yes, to some extent'. No one answered 'No, they did not'.



12. When you have important questions to ask your Clinical Nurse Specialist, how often do you get answers you can understand?

74% answered 'Always' or 'Most of the time'. With 1 respondent answering 'Some of the time' and one answering 'Never'.



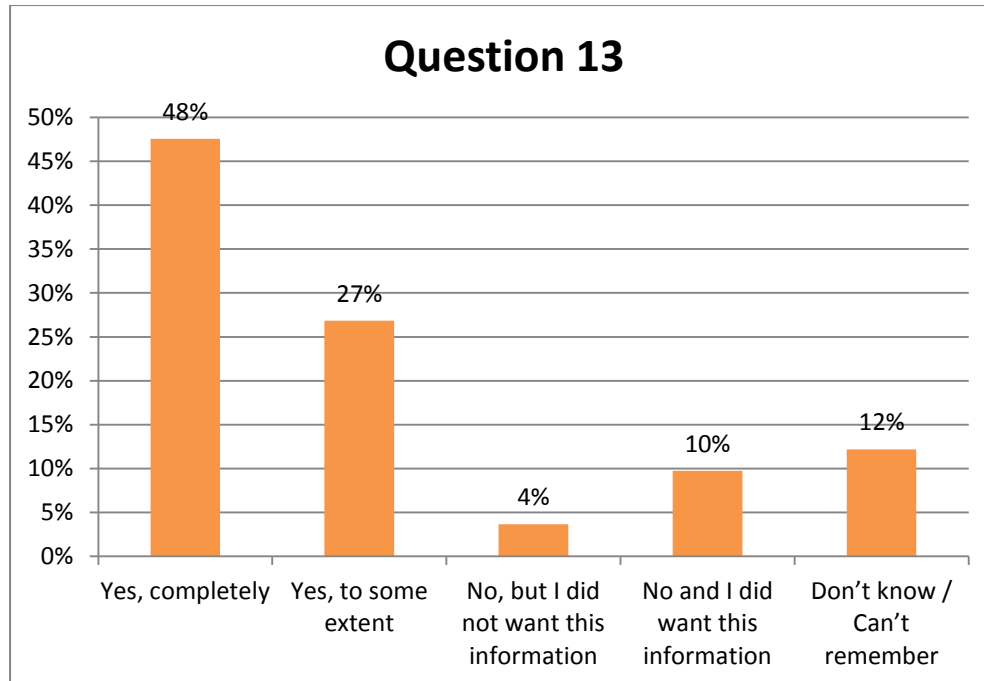
Results

- Three quarters of patients were given a name of a key worker at diagnosis
- Mostly easy to contact, but sometimes difficult which is expected due to hours worked
- "Very friendly and efficient service. Sue Brand always very helpful & let's you know she is never too busy to give you personal attention. "

Section 3 – Information and Support (related to appointments after treatment)

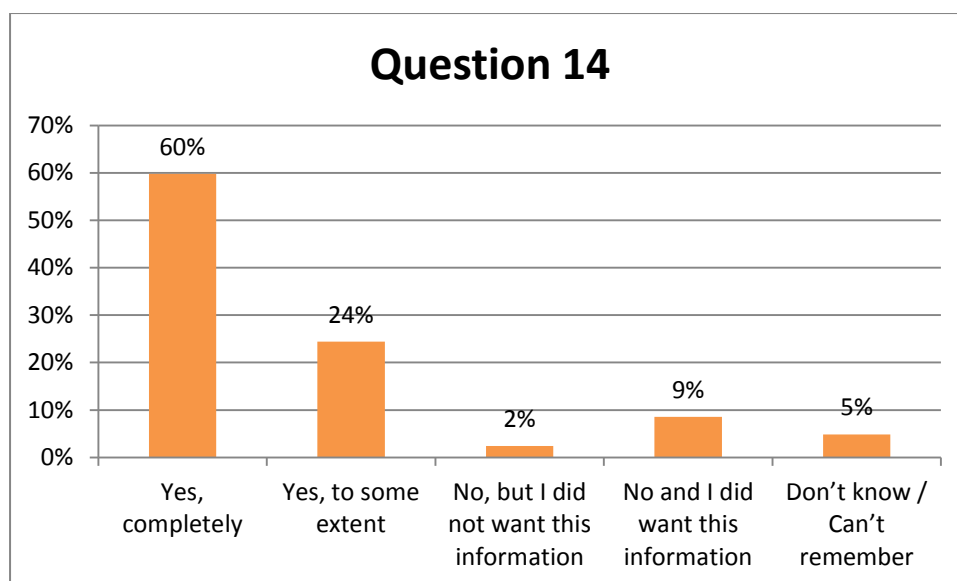
13. Have you been given information about the support available to you after your treatment?

Almost half the participants answered 'Yes, completely' with a further 27% answering 'Yes, to some extent'. 10% answered 'No, and I did want this information'



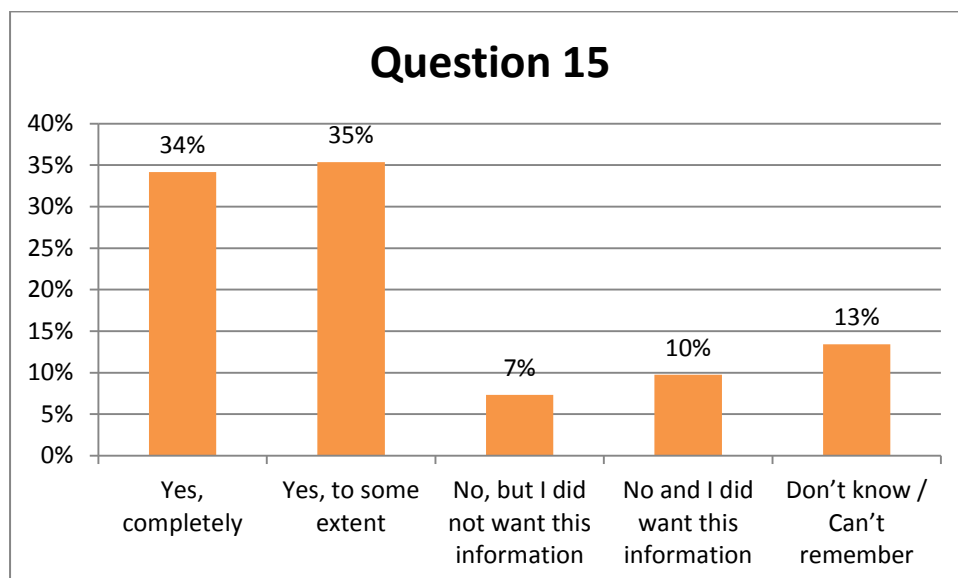
14. Have you been given information about your surveillance (follow-up) schedule?

60% of participants answered 'Yes, completely', whilst 24% answered 'Yes, to some extent'. 9% answered 'No, and I did want this information'.



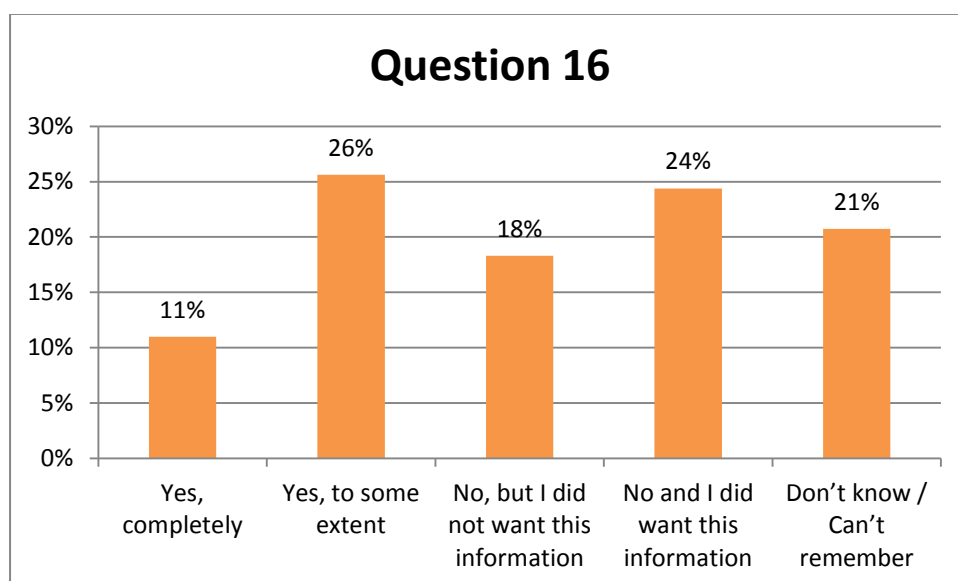
15. Have hospital staff give you information about support or self-help groups for people with cancer?

Just over one third of participants answered 'Yes, completely', with slightly more answering 'Yes, to some extent'. 10% of participants answered 'No, and I did want this information'.



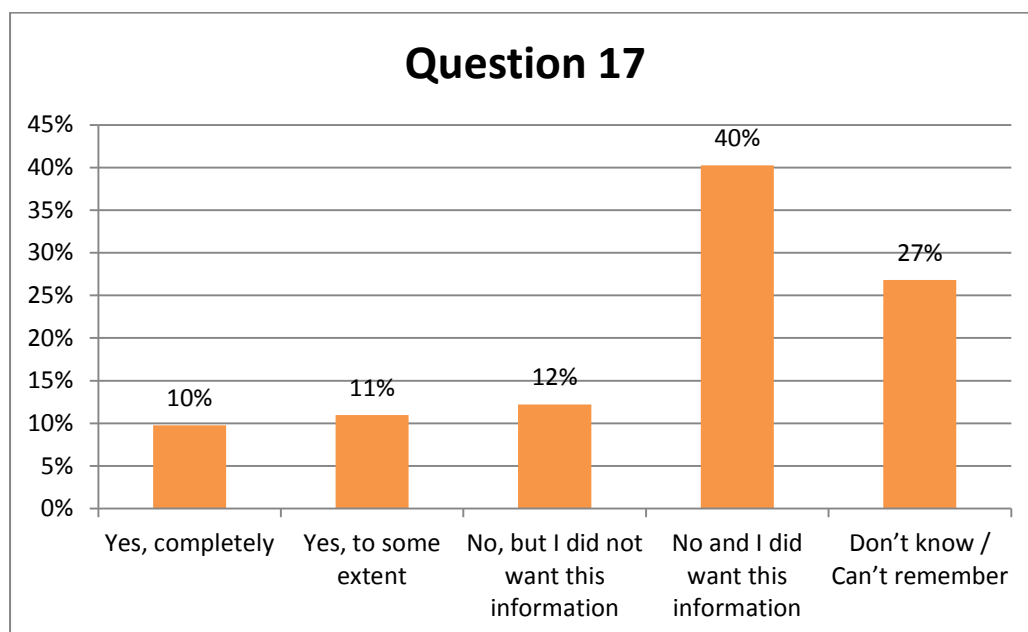
16. Have hospital staff given you information about how to get financial help of any benefits you might be entitled to after treatment?

Only 11% of participants answered 'Yes, completely' to this question. 18% indicated that they had not wanted this information, but 26% of participants answered 'Yes, to some extent' whilst 24% answered 'No, and I did want this information'.



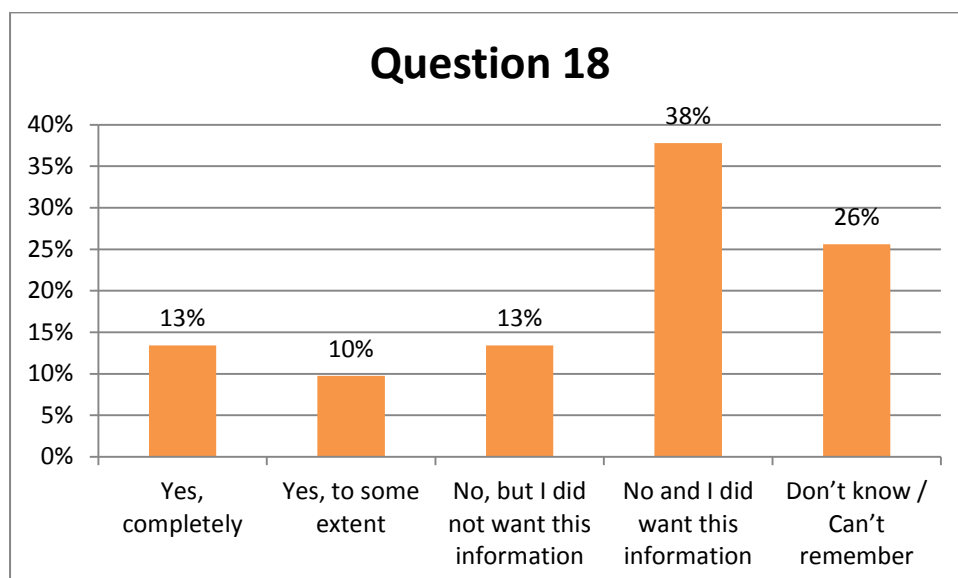
17. Have you heard or have knowledge of It's in the Bag travel grants?

Only 10% of participants answered 'Yes, completely' and a further 11% answered 'Yes, to some extent'. 12% indicated that they did not want this information, but 40% of participants answered 'No, and I did want this information'.



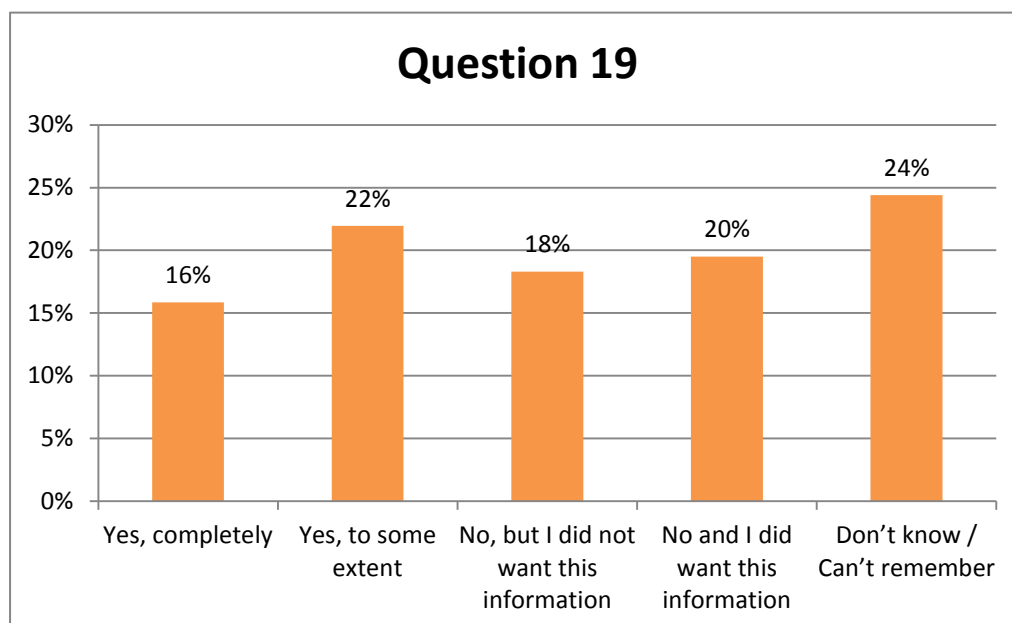
18. Have you heard or have knowledge of the Living Well Beyond Testicular Cancer Course?

This shows a similar distribution to Question 17, with almost 40% of participants answering 'No, and I did want this information'.



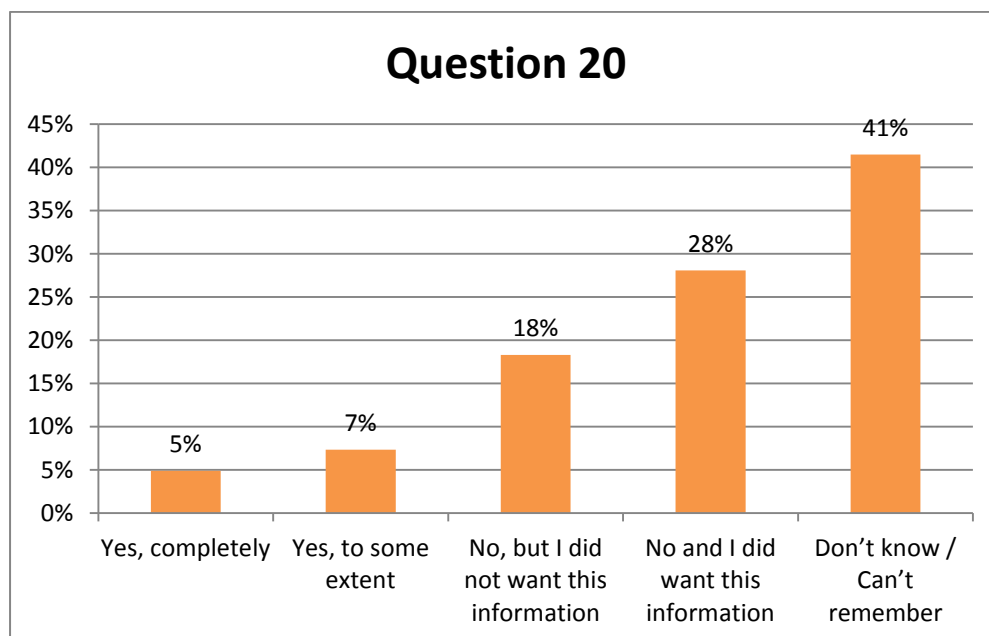
19. Have you heard of have knowledge of It's in the Banter Support Activities?

16% of participants answered 'Yes, completely', with 22% answering 'Yes, to some extent'. 18% of participants indicated that they had not wanted this information, but a further 20% answered 'No, and I did want this information'.



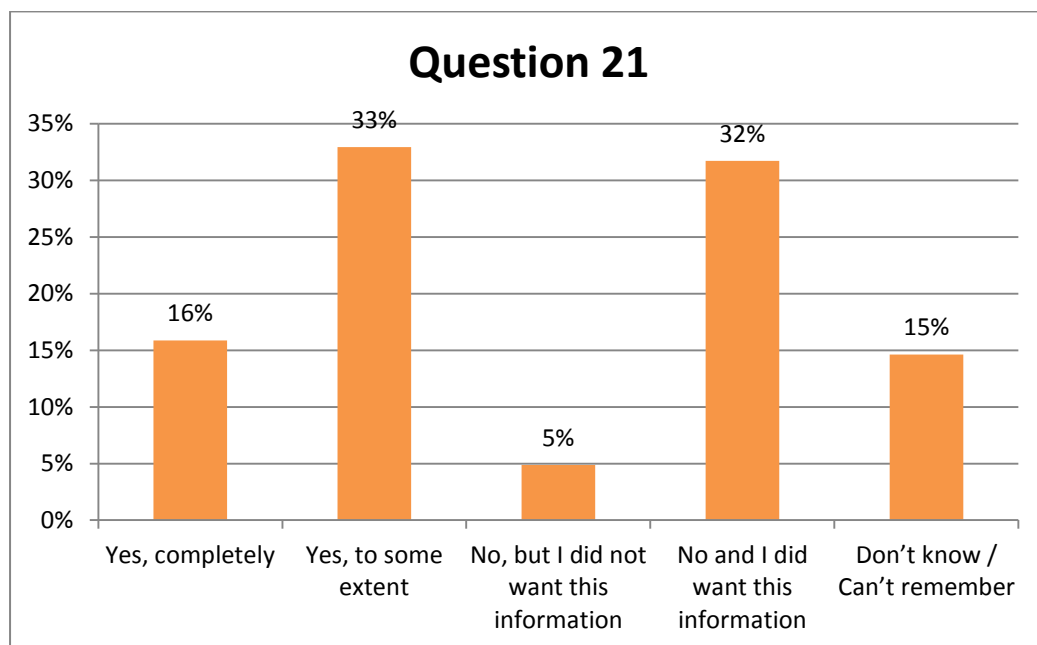
20. Have you heard of have knowledge of Get into your NEW PANTS?

Only 12% of participants answered either 'Yes, completely' or 'Yes, to some extent'. 28% answered 'No, and I did want this information', whilst 40% of participants said that they didn't know / couldn't remember.



21. Have hospital staff given you information about healthy lifestyles after cancer treatment?

16% of participants answered 'Yes, completely' to this question, whilst about a third each answered 'Yes, to some extent' and 'No, and I did want this information'.



Room for improvement

Key areas:

- Financial information & Benefits
 - It's in the Bag Travel Grants
 - Living well with the impact of testicular cancer course
 - Advice on healthy lifestyles
 - Self-help / support groups
- (45% indicated that they would have liked more information)

Recommendations:

- New patient information leaflet which will be given when patients come in for chemotherapy
- Nurse-led holistic needs clinic appointment post-treatment
- Macmillan cancer support worker available in clinic to give information about support and healthy lifestyles
- Patient volunteers (on-going project)
- Re-survey in October / November to evaluate progress

What the patients say:

- *"Always been treated well and with care. Never rushed and answered questions. Best part of National Health. Sue has been especially fabulous, always a smile and good morning. Don't know how she does it :)"*
- *"Best in the UK. Top notch all staff polite and professional."*
- *"Cannot fault the care and helpfulness of all staff. Very friendly and all knew my name. Made what can be quite stressful really easy."*
- *"I am happy with and grateful for all of my treatment and care at this hospital. It's because of you guys that I have my life back. You are all priceless."*